118TH CONGRESS
1ST SESSION

S. RES. _____

Expressing support for the designation of June 19, 2023, as ''World Sickle Cell Awareness Day'' in order to increase public awareness across the United States and global community about sickle cell disease and the continued need for empirical research, early detection screenings, novel effective treatments leading to a cure, and preventative care programs with respect to complications from sickle cell anemia and conditions relating to sickle cell disease.

IN THE SENATE OF THE UNITED STATES

Mr. BOOKER submitted the following resolution; which was referred to the Committee on _____

RESOLUTION

Expressing support for the designation of June 19, 2023, as ''World Sickle Cell Awareness Day'' in order to increase public awareness across the United States and global community about sickle cell disease and the continued need for empirical research, early detection screenings, novel effective treatments leading to a cure, and preventative care programs with respect to complications from sickle cell anemia and conditions relating to sickle cell disease.

Whereas sickle cell disease (referred to in this preamble as ''SCD'') is a group of inherited red blood cell disorders,

a genetic condition present at birth, and a major health problem in the United States and worldwide;

Whereas the 2023 theme of World Sickle Cell Awareness Day, ''Shine the Light on Sickle Cell'', is an immediate call to action to improve the health and quality of life for individuals living with SCD and their families;

Whereas, in 1972, Dr. Charles Whitten established the Sickle Cell Disease Association of America to improve research, education, and health care for SCD patients and which is now headquartered in Hanover, Maryland;

Whereas, in 1972, Congress passed the National Sickle Cell Anemia Control Act (Public Law 92–294; 86 Stat. 136), which, for the first time, provided authority to establish education, information, screening, testing, counseling, research, and treatment programs for SCD;

Whereas sickle cell trait (referred to in this preamble as ''SCT'') is a gene mutation that causes a single misspelling in the DNA instructions for hemoglobin, a protein that aids in carrying oxygen in the blood, and results in chronic complications, including anemia, stroke, infections, organ failure, tissue damage, intense periods of pain referred to as vaso-occulsive crises, and even premature death in individuals living with SCD;

Whereas SCT occurs when an individual inherits 1 copy of the sickle cell gene from 1 parent, and, when both parents have SCT, there is a 25 percent chance that any of their children will have SCD;

Whereas there are an estimated 3,000,000 individuals with SCT in the United States, with many unaware of their status;

Whereas an estimated 100,000 individuals have SCD in the United States, with 1 out of every 365 African-American births and 1 out of every 16,300 Hispanic-American births resulting in SCD, and nearly 1 out of 13 African-American babies are born with SCT;

Whereas SCD affects millions of individuals throughout the world, especially individuals of genetic descent from sub-Saharan regions of Africa, South America, the Caribbean, Central America, Saudi Arabia, India, Turkey, Greece, and Italy;

Whereas the variance relating to disease prevalence of SCT ranges greatly by region, with rates as high as 40 percent in certain regions of sub-Saharan Africa, eastern Saudi Arabia, and central India;

Whereas, in many countries that are poor in resources, more than 90 percent of children with SCD do not live to see adulthood;

Whereas approximately 1,000 children in Africa are born with SCD each day, more than ½ of whom will die before their fifth birthday;

Whereas the high prevalence of SCD in the central and western regions of India results in approximately 20 percent of babies diagnosed with SCD in those regions dying before the age of 2;

Whereas, in 2006, the World Health Assembly passed a resolution, adopted by the United Nations in 2009, recognizing SCD as a public health priority with a call to action for each country to implement measures to tackle the disease;

Whereas screening newborns for SCD is a crucial first step for families to obtain a timely diagnosis, to obtain com-

prehensive care, and to decrease the mortality rate for children with respect to SCD;

Whereas approved treatments for SCD are limited, with the Food and Drug Administration approving only 4 SCD therapies since 2017, but, as of the date of adoption of this resolution, there are more than 40 SCD therapies in development;

Whereas there is an immediate need for lifesaving therapeutics that can improve the duration and quality of life for individuals with SCD;

Whereas, in 2020, the National Academies of Sciences, Engineering, and Medicine developed a comprehensive strategic plan and blueprint for action to address SCD, which highlights the need to develop new innovative therapies and to address barriers to the equitable access of approved treatments;

Whereas, in 2020, the Department of Health and Human Services, in partnership with the American Society of Hematology and the SickleInAfrica Consortium, and in collaboration with the World Health Organization, hosted a webinar for a joint effort to strengthen efforts to combat SCD during the COVID–19 pandemic and beyond;

Whereas the late Kwaku Ohene-Frempong, M.D., Professor Emeritus of Pediatrics at the Perelman School of Medicine at the University of Pennsylvania, an American Society of Hematology member who founded and served as a member of the Global Sickle Cell Disease Network, was a leader in advancing the body of knowledge in SCD research, public health, and medicine and is recognized as immeasurably benefitting thousands of children worldwide;

Whereas there are emerging genetic therapy technologies, including gene editing, that can modify a patient's own hematopoietic stem cells to enable them to generate healthy red blood cells to prevent sickle cell crises;

Whereas hematopoietic stem cell transplantation (commonly known as ''HSCT'') is currently the only cure for SCD, and while advancements in treatment for complications associated with SCD have been made, more research is needed to find widely available and accessible treatments and cures to help individuals with SCD; and

Whereas, although June 19, 2023, has been designated as ''World Sickle Cell Awareness Day'' to increase public awareness across the United States and global community about SCD, there remains a continued need for empirical research, early detection screenings, novel effective treatments leading to a cure, and preventative care programs with respect to complications from sickle cell anemia and conditions relating to SCD: Now, therefore, be it

Resolved, That the Senate—

(1) supports the goals and ideals of World Sickle Cell Awareness Day;

(2) commits to ensuring equitable access to new sickle cell disease (referred to in this resolution as ''SCD'') treatments by shining the light among all economic, racial, and ethnic groups to improve health outcomes for individuals living with SCD;

(3) calls on the Department of Health and Human Services to create global policy solutions

aimed at providing support for the global community with respect to SCD and, in partnership with local governments, the domestic resources needed to provide access to newborn screening programs, therapeutic interventions, and support services with respect to SCD;

(4) supports eliminating barriers to equitable access to innovative SCD therapies, including cell, gene, and gene-editing therapies in the Medicare and Medicaid systems for the most vulnerable patients;

(5) encourages the people of the United States and the world to hold appropriate programs, events, and activities on World Sickle Cell Awareness Day to raise public awareness of SCD traits, preventative-care programs, treatments, and other patient services for those suffering from SCD, complications from SCD, and conditions relating to SCD;

(6) encourages the President to form a Sickle Cell Disease Interagency Group, which should include the Department of Health and Human Services, the Department of Veterans Affairs, the National Institutes of Health, the Food and Drug Administration, and the Centers for Medicare & Medicaid Services, to work toward policies that will sup-

port equitable and appropriate access to innovative SCD therapies; and

(7) with respect to the policies described in paragraph (6), urges the interagency group described in that paragraph to consider options that not only address access to potential future curative treatments for SCD, but also address the bias that the population most affected by SCD continues to face within the United States and global healthcare systems.